

HOW TO MAKE BEST USE OF RESOURCE INFORMATION

In a Well-Visit, be sure to ask families if they have any needs in the following areas. *The Note to provider* suggests a starting point to find information and resources.

Great Resource: State medical home teams are working on improving services and systems for CSHCN and their families. Contact them for further information and resources.

Home Health

- What type of home health services does your child receive (skilled/shift nursing, nursing visits)?
- Who provides these services (nurse, nurse aid)? How often?
- Are these services enough (do you have time or the ability to shower, get groceries, sleep)?

Note to provider: document this information on the care plan and keep in front of chart. Consult resource listings on health care in your community and state.

Respite

- Do you receive any respite (a break; time to rest and catch your breath)? Who provides it?
- Are there any people available to help you with caring for your child so that you can get a break? (I.e. a neighbor, friend, family member, respite program)
- Is your family connected with any state programs that provide funding for respite? (Department of Developmental Disabilities, Mental Retardation/Developmental Disabilities, Family Resource Centers, Social Service Agencies, etc)

Day Care

- Have you been able to locate a daycare provider who is comfortable and competent to care for your child with special health care needs?
- Are you satisfied with the ability of daycare to work with your child?

Note to provider: Child Care Aware is a nonprofit organization that helps parents locate quality childcare and relevant resources in their communities. Learn more about this program and the specific resources it offers through this Web site <http://www.childcareaware.org/>. Healthy Child Care America is a collaborative effort of health professionals, child care providers, and families seeking to improve the health and well-being of children in child care <http://www.healthychildcare.org>.

"Child Care Links Children with Special Health Care Needs to a Medical Home"
Refer to this article and checklist for information about providing children with special health care needs a medical home to help integrate them into the community and provide them the opportunity to become productive independent adults.
www.healthychildcare.org/pdf/summer2000hcca.pdf

Case Management/Care Coordination

- Do you have a Case Manager through:
☐ Department of Health ☐ Early Intervention ☐ Medicaid/CHIP ☐ Public Health Nurse ☐ Mental Health ☐ MR/DD ☐ Hospital Social Worker
- Do you receive any assistance in coordinating care for your child?

Insurance/Financing

- How are you covering your medical expenses?
☐ Private insurance ☐ Medicaid/CHIP ☐ CSHCN Program ☐ SSI ☐ Financial programs through MR/DD ☐ Other
- Do you need help understanding your benefits?
- Do you need any help with letters of medical necessity?
- Are you being covered by insurance for items like diapers, formula, and nutritional supplements?

Durable Medical Equipment (DME)

Some examples of durable medical equipment are:

- Feeding Utensils, for example spoons and cereal bowls
- Bath chairs
- Special Care Seats
- Highchair inserts
- Hospital Bed
- Walkers
- Strollers
- Wheelchairs /Kid Karts
- Special Seating
- Lifts (Hoyer/Trixie)
- Vans (special lifts, tie downs)
- Feeding equipment
- Respiratory equipment
- Monitors
- What equipment does your child now use?
- Is there any other equipment you need now or expect to need in the near future?
- Does any of your equipment need replacement, modifications or repair?
- What does your insurance pay for? Are you connected with other financial assistance programs to cover these expenses?
- Has the home been evaluated to support the recommended equipment?
- Have you had an assessment to see what types of equipment would be helpful and possible in your home?

Note to provider: Caregivers may not know what they need and you may need to prompt them by asking about their day and what challenges they have: Do you have trouble lifting your child, carrying supplies, getting in and out of the car, do you have alternate seating?

Before you offer to order DME consider the following: Is the equipment medically necessary? What is covered by the patient's insurance? Have you looked into equipment lending programs? You can contact Easter Seals, Hospital DME Departments, and

Community DME companies for used equipment. You can also call other patients and ask for donations of old equipment.

Home Evaluation: *An evaluation of the home may be necessary before ordering equipment to determine safety and access and overall needs. An evaluation can be done by an in home physical and or occupational therapist and or if a home care agency is involved, they may have staff to do an evaluation. You can also ask for a DME evaluation of your needs by a DME provider. A written prescription or physician order may be necessary.*

If home modifications are necessary to support the DME such as widening doorways, getting a custom built ramp, here is a list of possible contacts: insurance case manager or customer service representative, Easter Seals, community social service agencies, State waivers may include financial support for home modifications, Habitat for Humanity, faith based organizations, churches and temples, etc. For more information and resources regarding home modifications, go to:

<http://www.familyvillage.wisc.edu/general/homemods.html>

Dental Issues

- Do you have a dentist for your child?

School

- Is your child now, or did your child ever, participate in Early Intervention?
- Does your child have an IEP or 504?
- Where does your child attend school? (Name and District)
- Which services does your child receive at school? (OT, PT, Speech, adaptive physical education) How often? Individual or Group?
- Have you been satisfied with the IEP and planning process at school?

Transitions

- Are you preparing for any major transitions for your child – from Early Intervention to school? From one school/classroom to another; from adolescence to adulthood?

Note to provider: *consult resource listing in State Agencies. KY TEACH Project (Kentucky Commission for CSHCN and Shriners Hospital, Lexington)*

chs.state.ky.us/commissionkids/transition.htm

KY TEACH has various resources to assist young people and their families through the transition from school to work, pediatric to adult health care, and living at home to independent living. Examples include: Preparation for Transition Checklist, Age 17-21 Life Map and Teaching Sheet examples, Ten Steps to Job Success, Hiring and Using a Personal Care attendant, and how to be insurance savvy.

Recreation

- What typed of recreational programs does your child participate in?
- Does your child have an opportunity to attend camp or participate in a recreational program over the summer?

Clothing

- Do you need help finding specialized clothing – shoes (e.g. to fit over braces), outerwear, helmets, clothing suited to g-tubes, wheelchairs?

Note to provider: <http://www.familyvillage.wisc.edu/at/adaptive-clothing.html> provides a comprehensive list of organizations and web sites that offer adaptive clothing.

Housing/Home Modifications

- Is your housing situation meeting your child's healthcare needs?
- Are there any adaptations or equipment needed?
- Are you aware of the organizations that can assist with design and funding?

Note to provider: <http://www.familyvillage.wisc.edu/general/homemods.html> Provides a list of web sites on design and state resources. You can also contact Habitat for Humanity, Easter Seals, United Way, and other community agencies for possible resources and assistance.

Transportation

- Does your family have a handicapped placard or plate?
- Do you need any special assistance with transportation? (I.e. ambulance, ambulette, w/c accessible transport)
- Have you ever had a need for specialized long-distance transport to another medical facility?

Note to provider: Consult resources on Accessibility and Travel. Also, most municipalities have some form of accessible bus service. Medicaid often offers transportation for medical appointments, which includes therapies – call your county office for more information.

Family Support

- Are you involved in any support groups, as parents?
- How are the other children in your family doing? Do they think they could benefit from any programs for children who have a brother/sister with a special health care need?
- Would you like to be reaching out to other families in similar circumstances?

Note to provider: http://www.familyvillage.wisc.edu/general/frc_sibl.htm offers resources, web sites, books and articles for siblings. **The Sibling Support Project** is a national program dedicated to the interests of brothers and sisters of people with special health and developmental needs. The Project's primary goal is to increase the availability of peer support and education opportunities for brothers and sisters of people with special health and developmental needs. www.thearc.org/siblingsupport/

Regional Parent-to-Parent Programs http://www.familyvillage.wisc.edu/cof_p2p.htm
Family Voices Programs by State: <http://www.familyvoices.org/states.htm>

Information

- Would you like to have more information about your child's condition?
- Would you like to know about newsletters and other publications, which cover disability issues?
- Do you have access to the Internet? Would you like to know about disability related web sites?

Note to provider: http://www.medicalhomeinfo.org/weblinks/gen_med.html provides information on organizations and Internet sites that offer information on specific conditions/diagnoses.

For providers, another resource is the MedHome Portal: <http://medhome.med.utah.edu/> Offering information, tools, and resources for Primary Care Physicians to enhance their ability to care for Children with Special Health Care Needs (CSHCN) and to provide a Medical Home for all of their patients.

The MedHome portal is a web- information access resource with annotated references. A logical categorization and facile search function will enable physicians (and others) to easily find what they are looking for. Direct links to abstracts and, when available, full text will be provided, as well as links for ordering articles that are not available on-line.

Special Opportunities

- Are you aware of special programs available to families who have kids with special health care needs, such as: Make a Wish, Starlight, Miracle Network, and Children's Wish?

Note to provider: <http://www.familyvillage.wisc.edu/general/wish-grant-orgs.html> You can also contact state and local pediatric hospice programs and children's hospitals social service departments for further program information.